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Gene Week: a novel way of consulting the public

Mairi Levitt, Kate Weiner, and John Goodacre

Within academic circles, the “deficit” model of public understanding of science has been subject to increasing critical scrutiny by those who favor more constructivist approaches. These suggest that “the public” can articulate sophisticated ideas about the social and ethical implications of science regardless of their level of technical knowledge. The seminal studies following constructivist approaches have generally involved small-scale qualitative investigations, which have minimized the pre-framing of issues to a greater or lesser extent. This article describes the Gene Week Project, sponsored by the Wellcome Trust, which attempted to extend this work to a large-scale consultation on genetics and health through the medium of a local daily newspaper. Readers were invited to respond to a set of open-ended questions that accompanied stimulus material published each day for five consecutive weekdays. The articles were written with the intention of extending the limited range of discourses around genetics and biotechnology that are usually presented by the popular media (hope, fear, tragedy and bravery). Responses raised overarching issues about the place of emerging health technologies in society reminiscent of previous open-ended consultations in this field. The paper ends with a critical discussion about the potential of this method to contribute to the further development of open-ended public consultations.

1. Deficit models of “the public”

The notions of lay knowledge and lay expertise *may* seem so established within social science as to be no longer contested (Epstein, 1995; Kerr et al., 1998a; Popay and Williams, 1996) (but see Prior, 2003). Constructivist or contextualized models of the public understanding of science have all but replaced the “deficit” model although there is a continued interest in the relationship, if any, between “scientific knowledge” and attitudes towards science (Sturgis and Allum, 2004). There is evidence that within some parts of the United Kingdom government, lay expertise is also gaining recognition and status (House of Lords, 2000). However, within the science and science policy world the “deficit model” persists in shaping the thinking of many groups of actors (Michael, 2002). Kerr and colleagues have argued, for example, that scientists, biotechnology companies and national governments remain concerned about public ignorance as they see it as impeding technical progress in genetics and the potential economic opportunities (Kerr et al., 1997). Indeed, the British

Prime Minister, Tony Blair, has reportedly complained about an “anti-science fashion” in the UK and called for “an end to the air of suspicion and mistrust that sometimes surrounded the work of scientists and the misplaced fears and ignorance it often generated” (Webster and Henderson, 2002:1).

There now seems to be an imperative to consult the public and there has been a proliferation of consultations in the field of biotechnology and health. In the UK these consultations have been initiated both directly by public bodies including the Wellcome Trust, the Medical Research Council, the Human Genetics Commission and the Human Fertilisation and Embryology Authority and through research funding, in particular by the Wellcome Trust (HGC/HFEA, 2001; HGC, 2002; Nuffield Council on Bioethics, 2002; Wellcome Trust/MRC, 2000; Wellcome Trust, 2003). As Harrison and Mort (1998:61) comment: “being in favour of better public consultation . . . is rather like being against sin; at a rhetorical level, it is hard to find disagreement.” Yet, any discussion of public consultation has to be seen in the context of the different conceptions of the public. It is therefore unsurprising that there is no consensus about who should be consulted and to what end. There appear to be four disparate premises underlying this drive to consult, which link to different conceptions of the public.

1. Better understanding of science will lead to greater acceptance, based on the premise that ignorance leads to hostility (Voss, 2000; Wellcome Trust, 1998).
2. The basic trust in science and science governance needs to be restored, through openness and dialogue with the public. In the UK this had been prompted by a number of science policy crises (Dickson, 2000; House of Lords, 2000).
3. The need for greater public involvement in all spheres of public policy, at both local and national level, may be seen as a possible supplement to the inadequacies of representative democracy or the “democratic deficit” (Cooper, 1995; Harrison and Mort, 1998).
4. Lay people have important expertise, based on context, location and experience. This expertise has an essential role in the production of scientific knowledge (Kerr et al., 1998b; Irwin and Wynne, 1996; Wynne, 1996).

The first premise clearly links to a “deficit” view of public understanding; the fourth is a constructivist position, while points 2 and 3 are compatible with either of these. The debate over public involvement in scientific decision-making continues as shown in Collins and Evans (2002) and the ensuing commentaries on their article. Collins and Evans have tried to delimit exactly who counts as having expertise in any area, whether credentialed or not. Their critics have problematized the boundary between science and politics and argued that public participation is not only about the public having particular expertise but also to do with realizing democracy and providing oversight of powerful institutions (Jasanoff, 2003; Wynne, 2003). The debate illustrates the continued intense interest in the nature of scientific expertise and the interrelationship between science and society.

2. Methods of public consultation

Established methods for public consultation range from large-scale surveys to citizens’ juries, the choice of method being dependent on the aims of the consultation and the underlying view of science and expertise held by the researchers. While enthusiastic rhetoric about public consultation can mask a lack of clarity about who the public are and what their role should be, the way the consultation is conducted tends to be revealing on these points. National bodies that advise on policy, such as the Nuffield Council on Bioethics (2002) and

the Human Genetics Commission (2002) have tended to undertake consultations by inviting known expert individuals and organizations to respond. While not precluding ordinary people from the consultation this approach means that the focus and the bulk of replies are expert responses. The implicit assumption is that credentialed experts, of whatever discipline, are the relevant members of the public. Citizens' juries have been seen as a method that empowers a group of "ordinary" people to participate actively in decision-making. Critics have pointed out that in practice the agenda may be pre-framed by scientific "experts" circumscribing what counts as relevant and leaving the public a reactive role (Dunkerley and Glasner, 1998; Purdue, 1999). Here the public is seen as able, with expert guidance, to adjudicate between different technical solutions but as unable to raise new and alternative questions based on their own experiential knowledge.

Other methods of consultation are premised on the idea that lay people have important and distinctive expertise and there should be opportunities for this to be expressed. Kerr and colleagues, and Barns and colleagues both used focus groups in a way that allowed participants to move beyond established notions of what is relevant and interrogate assumptions about health and illness (Kerr et al., 1998a; Barns et al., 2000). Although focus groups are more likely to embody a constructivist perspective, in practice any method can embody either a constructivist or a realist model of science. We would argue that the aims and outcomes of a consultation are related not only to the method employed but also to the way it is implemented. Therefore, we need other ways of differentiating between methods. A number of criteria have been suggested for evaluating public consultations. The recurring criteria are: whether there is a *deliberative* element, that is, an opportunity to discuss the issues being raised; what type of substantive *information* is provided, if any; which groups of people are involved and any *selection* process; how the *agenda* is set and framed; the degree of *influence*, if any, of the findings (Finney, 1999; Harrison and Mort, 1998; Irwin, 2001; Rowe and Frewer, 2000).

3. Gene Week

The rest of this paper will focus on the "Gene Week" research project, outlining this new method of consultation and evaluating it on the basis of the previous discussion. Gene Week was funded through the Wellcome Trust program on *novel* means of consulting the public about genetics. The consultation was centered around a series of articles on genetics and health that were published in a local daily newspaper. The aims were to undertake a widely accessible consultation which would engage people as ordinary citizens, rather than targeting organizations and professionals; to provide information without the hype often associated with media reporting; and to allow participants to raise the issues they thought were important in the ways they wanted to, by enabling them to have some control over the agenda. Overall the consultation was premised on the view that the general public/s have valuable ideas to contribute to debates about genetic technologies and their application.

Study design and method

During one week in March 2002 five articles on health and genetic technologies were published in Preston's daily newspaper, the *Lancashire Evening Post* (LEP) and on its associated website.¹ The project was undertaken in collaboration with the news editor of the LEP who allocated a full page per day. The articles were written by the researchers and refereed by an external panel including scientists, social scientists, health professionals and

ethicists to verify the technical, social and ethical aspects. Topics included genetic testing, prenatal and pre-implantation genetic diagnosis, cloning, biobanks and xenotransplantation. The articles were not simply providing scientific information. It was our intention to discuss some of the scientific details in order to highlight the social, ethical and policy issues associated with developing and applying genetic technology. The articles drew on local material, personal experiences and the views of different kinds of experts, credentialed and non-credentialed, for example, a local genetic counselor, local deaf students, a young woman with cystic fibrosis and geneticists. For example, the second article, published 19 March 2002, began with a section on prenatal testing discussing the choices available after testing, which are usually either to continue with the pregnancy or to terminate an affected fetus; the emphasis on individual choice in screening programs and concerns raised by routine screening. In the full article deaf students from the local university gave contrasting views on the desirability of genetic diagnosis for their own condition. There was an explanation of pre-implantation genetic diagnosis (PGD) with a discussion of the current and potential uses of PGD (including for example non-medical reasons such as “family balancing”) and the criticism that PGD involves the “commodification” of children. The story of the Hashmi family, who were seeking to use PGD at the time, was included with a photograph. The article contrasted the hype of designing for physical and behavioral characteristics with the status of current knowledge and practice. Each article included two or three open-ended questions relating to the day’s material and readers were invited to send in their views under the heading “What do you think?” The questions were designed to stimulate *any* response not to obtain information on specific topics and questions were also used throughout the article. Respondents treated the questions as we intended, that is, they did not necessarily answer each or any of the questions but chose some questions and/or gave their views on other points. We were not assuming that the readers were ignorant of science or of genetic applications but wanted a way to solicit their views. In responding people could, and did, draw on their knowledge in other areas and their previous experiences.

Each day’s questions were placed on a form at the end of the article. This was followed by a set of tick box questions to collect basic demographic details about the respondent’s age, sex, ethnicity and occupation. Readers were asked to write their views on a piece of paper and to enclose the completed form (see Figure 1). To encourage responses a freepost facility was provided and a prize draw with £20 of gift vouchers was offered for respondents. In addition about 300 free copies of the newspaper were distributed each day to selected local groups, such as an engineering works, an Islamic Centre and a comprehensive school. These copies included an inserted response sheet and freepost envelope.

The project design was novel in a number of respects. First, it was designed to elicit open-ended responses at the same time as employing a large-scale rather than a selective consultation (the LEP has a circulation of around 57,000). Second, the open-ended questions contrast with most media-based consultations that tend to use opinion polls often only allowing yes/no responses to complex questions.² Third, use of a local newspaper provided a potential means of targeting people whose perspectives are less likely to be represented in consultations that do not involve sampling on socioeconomic characteristics. Only eight percent of LEP readers are from social classes A or B (professional and technical occupations). The LEP did not contain any general coverage of genetics or health issues in the year preceding Gene Week and around one-third of the readership do not take another daily paper. Fourth, in response to criticisms of the usual media reporting, the articles were written to focus on the implications of current applications and research, showing the complexity of issues and avoiding hype. The UK press has been criticized for reporting

What do YOU think?

WOULD YOU WANT A PIG'S HEART? SHOULD HUMAN CLONING BE ALLOWED?

Write down your views and complete the form and you could win one of our £20 gift vouchers. Send to FREEPOST GENE WEEK. Nothing else is required on the envelope, not even a stamp.

You can also send your views via the website www.prestononline.co.uk

The information on this form is for the researchers only and will not be passed on.

Male ☐ Female ☐
(Please tick)

Age group (please tick)
 17 or under ☐ 18-25 ☐ 26-40 ☐ 41-60 ☐ 61 and over ☐

Ethnic origin (please tick)
 White ☐ Asian ☐ Black ☐ Mixed ☐ Other ☐

Occupation

To be entered for the prize draw, please give your name and address:

Name

Address

.....

Mairi and Kate would like to contact a few people after Gene Week to see what they thought about it. If you are not willing to be contacted please tick here ☐

Figure 1. Form and questions (Wednesday's article).

scientific “breakthroughs” in an uncritical way, with neither the uncertainties nor the social context discussed (Kohring and Gorke, 2000; Petersen, 2001; Zimmerman et al., 2001). As Smart's analysis of the coverage of the “first draft” of the Human Genome Project showed, even where ethical, legal and social implications (ELSI) are raised “coverage of long-standing ELSIs was often formulaic, while the more novel concerns were usually framed by sensationalist news values or inspired by the hype surrounding the announcement” (Smart, 2003:45).

The response

In total 69 people responded from the general readership of the LEP, 21 by e-mail and 48 by post. This number of responses is similar to the numbers of responses obtained to competitions run by the newspaper (see observations below for further discussion of the number of responses). Although some 1400 free papers with inserts were distributed during the week, these elicited just 18 postal responses. In addition, the Gene Week material was used by a local comprehensive school in general studies classes during the week and we

received responses from 119 students. The Gene Week web pages were accessed by 171 unique visitors. Responses came from a wide variety of people, but compared to the readership profile there were relatively high proportions of women (63 percent), retired people (31 percent) and professionals (23 percent). In contrast to other consultations open to the “general public” (Human Genetics Commission, Nuffield Council, Human Fertilisation and Embryology Authority), no one responded to Gene Week in their official professional capacity or as a representative of any organization.

There were three distinct types of response from the general readership: first, completed forms only, with no further comments, returned by post; second, short comments (sometimes a single word) written on the completed form; and third, written comments on a separate sheet or returned by e-mail, accompanied by a completed form. Comments ranged from one word (“never” to cloning) to more than 750 words, with a median of 52 words. The postal responses indicated that what the readership were being asked to do was not as clear as we had assumed, because some coupons were returned without comments. While some responses were typed or handwritten in a formal style, others were written as people would speak. Some came on slips of paper, the backs of used envelopes or “Post-it” notes; others came on A4 sheets and writing paper. The format of the responses suggested that for some respondents, writing was not a regular activity and therefore they were being asked to engage in quite a demanding task.

School students’ responses were overall longer and tended to discuss both pros and cons in an hypothetical style in keeping with scholastic expectations, as illustrated in the following extract:

081: The tests which people can have to find out if they have inherited a disease are good, but only for those who want them. I agree that it can sometimes make things worse, if people receive bad news and they adopt the attitude “if I’m high risk, I might as well do what I want”, so I think it is the individual’s choice whether to have the tests or not. Everyone reacts differently in these situations but the fact that these tests are available is good.

In contrast the general readership tended to make punchy, specific points, personally identifying with the issues. Nevertheless there was still a range of responses, from discursive comments, for example;

014: Morally I would say you shouldn’t put any animal parts into humans but I think if it was a family member or close friend I would want them to have the best quality of life possible and if this meant living with a pigs heart or such like then I would have to agree. I don’t agree with clones of human or animals in the sense that something always seems to go wrong 10 years down the line after implementation, as we now read Dolly has arthritis. For illness I agree with genetics, for behaviour I am undecided.

002: I think caution should be shown with regard to PGD [pre-implantation genetic diagnosis] in terms of the restrictions or lack of them that could be put on parents. We are in danger of endeavouring to achieve the “perfect race” and dismissing the contribution of all members of society to our society.

to straightforward endorsements or criticisms of genetic research, for example; 022: “Giving a donation for research wouldn’t worry me or any research on genes.”

As described above, the method was designed to enable complex or ambiguous views to be expressed. Asking people to write their views down, resulting in fairly short responses, might seem like a barrier to this aim. Yet, the two discursive examples given show that respondents were able to pack a lot of issues within a small space. Response 014 above

manages to refer to the following issues in only 98 words: the conflict between morality, in general, and morals in practice; conflicting moral principles (the instrumental use of animals versus the imperative to improve quality of life for humans); safety and scientific probity and appropriate areas for genetic developments.

Why did people respond?

As discussed above, responding to Gene Week involved a relatively complex process. To address the reasons why some people were prepared to make this effort, follow-up work was undertaken with around one-third of the respondents, including equal numbers of men and women, covering different ages and occupational groups and a range of views. Follow-up was undertaken by e-mail, for e-mail respondents, or otherwise by telephone interview. People were asked what they had written about and why they had responded. On the basis of these limited data people's views appeared to be relatively stable. Even those who could not remember what they had written about gave views consistent with their original response.

A number of reasons for responding to Gene Week were offered. Whilst these replies represent motivational accounts, it is nevertheless interesting to note the kinds of reasons proffered. Some mentioned a personal connection to genetic health technologies (through illness, occupation or pregnancy). Some explained that they wanted to register support for or concern about *genetic research* or wanted to help or contribute to *our research*. Some drew on a repertoire of active citizenship or civic duty ("I just wanted to be public spirited really") and talked about their civic activities in other areas such as blood donation and charity work. Two people stated that they had responded because of the prize draw.

Four people were included who had originally returned only the completed coupon and might have responded solely because of the prize draw. However, of these, the two who could remember why they had responded gave clear motivations for their responses:

People should try and help you. It gets a bad press though, people think it's messing with science, but it's important, a good thing. If I could help you in any way.

I only respond if I'm really interested. Must have been because that's what you wanted.

These comments support our suspicion that it was not obvious how to respond to Gene Week, and suggest that in returning the form people may have been simply registering their interest in the project.

Analysis of the comments

The main purpose of this paper is to discuss the method, rather than the substantive findings which have been discussed in more detail elsewhere (Levitt et al., 2004). However, a brief exposition of the analysis is provided to illustrate what can be done with the data that were elicited. Similar lines of arguments emerged from responses to different questions. The recurring themes were identified from the data and comments were coded into these themes using NVivo 1.1 for data management. Three main overarching themes were identified:

1. Moral reasoning. This included ideas about personal choice both privileging choice and critiquing it, what constitutes quality of life and the place of humans in the world—particularly our relationship to animals and to nature.
2. Health policy. This included ideas about priorities, rationing (e.g. what will happen as people live longer?) and regulation.

3. Science in context. This included ideas about the socioeconomic context of science, safety aspects and people's hopes and expectations of science.

These themes overlapped in responses as exemplified in the two extracts below. Response 060 is an example of both moral reasoning and science in context. The respondent suggests that whether a genetic application is right or wrong depends on the society in which it is being used.

060: I would not personally select an embryo on the basis of gender, but don't actually have any moral objection to others having the right to do so, providing that this is in the context of a society that values both sexes.

The second extract is about both science in context and health policy, questioning research priorities in the light of uncertainties:

012: I'd be worried about having a pig's heart—how can we know whether it would have the same capabilities as a human's heart. We are still having a lot of rejection in terms of human to human transplants. Wouldn't it be better to concentrate resources in this area?

It is notable that these findings are similar to those of other consultations that allowed open-ended responses on this topic (Barns et al., 2000; Kerr et al., 1998b; Levitt, 1997, 1999). Respondents often had a broad perspective on genetics, rather than thinking about applications in isolation. In public debates on genetic applications there tends to be a ritualized lining up of participants on opposing sides of the debate. Our data suggest that, left to their own devices, people grappled with a range of arguments so that responses were not easily pigeonholed into "for" or "against." Further, respondents often considered social, technical and ethical aspects at the same time rather than confining themselves to the usual disciplinary boundaries. They were prepared to ask fundamental questions about the role of science in society; for example, who stands to benefit? Does the problem require a technological solution?

Observations on the method

Whilst the number of respondents might appear to be low, there was no benchmark for comparison as it was a novel method. Public bodies in the UK, such as the Nuffield Council on Bioethics, the Human Genetics Commission and the Human Fertilisation and Embryology Authority, have also undertaken a number of consultations that are open to anyone. These are generally announced in the national press, are freely available on paper or via the website and are mailed to selected individuals and organizations. Typically the consultation period runs over several months. Nevertheless, these national consultations typically attract similar numbers of responses overall to Gene Week, with most coming from organizations or people responding in their professional capacity³ (see Table 1 for further details). In the light of this, a local newspaper consultation of this type potentially offers a good way to access "ordinary" non-aligned people without undertaking any kind of sampling.

Although it was intended that responding to Gene Week should be as easy as possible, it was novel both in the medium used for the consultation and in how people were asked to respond. It is not surprising therefore that responses were not always as expected, for example some people sent in a completed coupon without providing any views and others sent in views about the newspaper unrelated to Gene Week. It is likely that these unexpected responses were in part due to the method. Providing blank lines on the reply form to write responses might have clarified what we were asking people to do and solved the difficulty of

Table 1. Examples of national consultations by public bodies in the UK.

Organization	Date	Report	Submissions
Nuffield Council on Bioethics	March 1996	Animal to human transplants: the ethics of xenotransplantation,	55 total – 5 private individuals – 1 group of 6th formers
Nuffield Council on Bioethics	Sept 1998	Mental disorder and genetics: the ethical context	120 total – 78 organizations – 6 affiliated individuals – 35 individuals—no affiliation – 1 group of 6th formers
Nuffield Council on Bioethics	May 1999	Genetically modified crops: the ethical and social issues	118 total – 48 organizations – 20 affiliated individuals – 48 individuals—no affiliation – 1 petition – 1 group of 6th formers
HGC/HFEA	Nov 2001	Outcome of the public consultation on preimplantation genetic diagnosis	171 total – 47 organizations – 127 individuals (no further details provided of affiliation)
Nuffield Council on Bioethics	Oct 2002	Genetics and human behaviour: the ethical context	111 total – 37 affiliated individuals – 27 individuals—no affiliation
HGC	May 2002	Inside information; balancing interests in the use of personal genetic data	181 tick box responses 86 detailed comments on main document – 64 organization – 22 individuals
HFEA	2003	Sex selection: options for regulation	52 discursive responses 589 questionnaire responses – 66 organizations – 574 individuals (no further details provided of affiliation)

finding paper to write on, but not the effort involved in writing. This idea was rejected because: it would have taken up valuable column inches, newsprint is not easy to write on and it would have suggested that a specific length of reply was expected. A possible solution, budget permitting, might be to provide a folding insert, pre-addressed with the form and a blank space for replies. However, a more fundamental possibility is that the readers of the LEP are simply not used to being consulted, despite the burgeoning consultation industry, and particularly not in an open-ended way. It is possible that this approach would need to become more commonplace before its full value could be realized.

Evaluation criteria

As described above, five main criteria by which consultations can be characterized were drawn from the literature. Taking the first of these, Gene Week provided no formal deliberative element, although sixth-form students did discuss the articles, before responding individually. The general LEP readers also had ample opportunity to discuss the issues and

anecdotal evidence suggests that in some cases the articles prompted discussion with friends, colleagues and family. Nevertheless, to introduce a formal deliberative element would have required specific locations to undertake the consultation (requiring either open meetings or soliciting specific groups).

The second criterion is whether or not information is provided before people are asked for their views, although this cannot be separated from the framing of the consultation (see below). The Gene Week articles were a fundamental part of the project. Much effort was directed towards integrating the technical, ethical and social elements of genetic health applications in a way that would interest readers and conform to expectations of personal stories and a local angle.

The third criterion is the selection of those to be consulted. Gene Week provided an opportunity to undertake a large-scale consultation, without having to select a limited sample, at the same time as focusing on specific groups whose views are less often heard. Whilst the readership of the LEP reflects these underrepresented groups, our success in accessing their views was limited.

The fourth criterion is the degree to which the agenda is set. We would argue that any and every consultation method has a degree of pre-framing, if only in the fact that, to borrow from Dingwall, people know they are being “put on notice to talk about *something*” at the researchers’ instigation (Dingwall, 1997: 58, emphasis in original). Pre-framing can be seen as a continuum. Structured questionnaires with closed questions are clearly pre-framed since respondents must answer a set of predetermined questions, choosing from a series of predetermined options, which embody the researchers’ stance. Any method requiring open-ended responses is pre-framed to a greater or lesser degree depending on how participants’ views are deemed admissible or inadmissible to a particular consultation, and, where there is expert input, the type of expertise sought (Irwin, 2001). In this study, to an extent the articles framed the agenda in terms of a focus on technology in use and the associated ethical and social issues and in asking particular questions to prompt responses. However, the design was more open-ended than other consultations on genetics, in the sense that people were free to respond to any of the questions or raise other issues, and did so. We had neither the opportunity nor the desire to guide people towards particular topics or to designate certain areas as irrelevant, as might happen in a focus group, citizens’ jury or interview.

The final criterion is the degree of influence, if any, of the findings. The project was funded by the Wellcome Trust to develop a new method of consultation and there was no direct connection to policymakers in the commissioning or reporting of the research findings. It is conceivable that if there had been a direct and explicit influence on a local policy issue, for example the drawing up of eligibility criteria for *in vitro* fertilization funded by the National Health Service locally, more responses might have been elicited. Indeed, more responses might have been obtained if we had focused on local service issues even if the responses did not feed directly into policymaking. However, Gene Week was designed to provide an overview of current and future applications of genetic technologies to health care and to prompt readers to engage with the issues these developments might raise for them and their families. One of the aims was to increase public awareness, not from the assumption that people needed any specific technical information on genetics, but to draw attention to developments that could have an impact on people’s lives. To have 5,000 words on genetics and health published in a local newspaper was a major success in the sense that the newspaper had not previously covered any of these issues nor did it carry articles discussing concerns relating to health and technology. There were stories of local people with health problems, especially young children, but their treatment and the use of health

care technology, if mentioned, was described rather than discussed (*Lancashire Evening Post* website).

4. Conclusions

The focus of the project was to present and evaluate a novel method. Nevertheless, there are major issues about the role of public consultation and we have argued that there should be more clarity about the aims of public consultation and the model of the public (or lay people) subscribed to by those commissioning and undertaking such consultations. Our results suggest that there is potential for this method as a way of accessing people as private individuals, although as usual middle class people were overrepresented compared to the readership. We recognize that there was a low number of respondents in relation to the readership but, nevertheless, compared with other consultations on genetics and related technologies open to everyone it was relatively successful. A number of possible ways of increasing the responses have been discussed, some were in keeping with the ideas behind Gene Week but others would have fundamentally changed the method. The experience of working with a local newspaper was positive. The staff were interested in the collaboration with their local university and happy to accept ideas and copy. The local newspaper provided a good medium for discussing issues of national interest at a local level, despite the fact that this differed from its usual coverage.

Research commissioned by policymakers tends to ask specific questions about a proposed policy in order to decide how to implement a particular technology or application in ways acceptable to the public (People Science and Policy Ltd, 2002). This approach does not tend to allow scope for concerns and issues about the wider context of these technologies. By contrast, Gene Week was successful in providing a more open-ended consultation; people did feel able to discuss a range of issues whether or not we had raised them specifically. The themes raised in Gene Week were similar to those raised in previous open-ended consultations, even though the replies to Gene Week were relatively short and drew on a different population (e.g. Barns et al., 2000; Kerr et al., 1998b; Levitt, 1997, 1999). The findings reiterate the point that people have fundamental questions about the governance of science and technology, which cannot be addressed through tightly framed consultations.

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Notes

1 Lancashire Evening Post website archive (accessed 20 May 2004) <http://www.lep.co.uk>.

2 Two examples of media-based consultations:

BBC Hot Topics—Intelligence—Nature or Nurture?

Do you inherit intelligence from your parents?

Yes ☐

No ☐

(accessed 13 July 2004) <http://www.bbc.co.uk/science/hottopics/intelligence/clever.shtml>.

geneforum.org—building an informed citizenry for the gene age

Participate in an interactive scenario on genetic engineering!

If you could choose some of the genes that your child will inherit, would you do it?

yes no maybe

(accessed 13 July 2004) <http://www.geneforum.org/getinvolved/igm>.

- 3 The exception may be the HFEA consultation on sex selection, see Figure 2, but this consultation was based on a questionnaire (HFEA, 2003).

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